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Abstract

Background People with intellectual disabilities are thought to have a reduced capacity for understanding death. Drawing on cognitive theory, researchers have suggested that those with profound intellectual and multiple disabilities mainly perceive loss as a mismatch between past and present experiences. However, very little research has considered how carers conceptualise bereavement in relation to this group. *Method* Semi-structured interviews obtained responses from 7 carers. Transcripts were examined using Interpretative Phenomenological Analysis. *Results* Two super-ordinate themes emerged: ‘difficulty articulating the experience of loss’ and ‘making sense of bereavement through familiar patterns’. *Conclusions* Carers conceptualise bereavement primarily in cognitive terms, but also take account of relational factors mediating loss. Implications for training and further research are outlined.

Keywords: profound intellectual and multiple disabilities, bereavement, carer, family, grief

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Title Page

Making sense of bereavement in people with
profound intellectual and multiple disabilities: carer perspectives

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Making sense of bereavement in people with profound intellectual and multiple disabilities: carer perspectives

Significant losses can lead to a range of painful emotional and somatic experiences. Whilst research into bereavement and loss has focused mainly on children and adults, there has been a growing stream of studies concerned with intellectual disabilities (IDs) (see Dodd *et al*, 2005 for a review). These studies have focussed principally on mild to severe ID, with limited attention paid to people with profound intellectual and multiple disabilities (PIMDs). Consequently, not much is known about the experience of or response to loss in this group, or how these may be conceptualised. Related to this, research has revealed the difficulties with which carers find providing bereavement support (e.g. McHale *et al*, 2009; Morgan & McEvoy, 2014). Likewise, few of these studies have included carers of people with PIMDs (e.g. Handley & Hutchison, 2013; Young & Garrard, 2016). Therefore, the current study focusses on this neglected but important area, by engaging with carer perspectives.

Viewing bereavement experiences from a cognitive perspective

It was previously thought that people with IDs were unable to grieve (Hollins & Kloeppel, 1989), although this view is now widely regarded as a severe failure to appreciate human capacity for emotion alongside cognitive impairment. However, more recently it has been suggested that people with PIMDs do not exhibit reactions of mourning (e.g. crying), due to their limited understanding of death (Meeusen-van de Kerkhof *et al*, 2006). A systematic review of the bereavement and ID literature reveals that this is the only published paper that explicitly attempts to conceptualise bereavement in this group (Young, in press). Using a framework primarily grounded in cognitive theory (Piaget, 1954), the authors rationalise overt behaviours (e.g. looking for the deceased) as responses to a mismatch between past and present experiences. Following from this, it is suggested that support for persons with PIMDs include concrete experiences, such as touching the dead person. In

contrast, the framework proposes a deeper understanding and a more sophisticated response to loss in mild ID. At this level, individuals are thought to be capable of engaging with the ‘normal’ process of grieving and can be supported by participation in ritual. This framework can be said to place people with IDs on a continuum of capacity and makes suggestions of support accordingly.

Research has not yet engaged with the question of whether the perceptions of carers of people with PIMDs differ from those above. Yet this is a significant question, since the perception that loss fundamentally rests on a person’s understanding has major implications for the type of support offered to the bereaved, if at all (McHale *et al*, 2009). For instance, in McEvoy & Smith’s (2005) study, family carers were unsure about the appropriateness of counselling, and it is likely that this is further complicated in relation to supporting people with PIMDs. It may be that awareness of this complexity inhibits carers and professionals from offering support. The reality for the bereaved person, however, is that their grief is disenfranchised (Doka, 2002); there is little social recognition of their felt pain because of factors related to their disability. An example of this can be found in the classic study of Hollins & Esterhuyzen (1997), in which over half of carers associated an increase in challenging behaviour to the ID rather than to a recent bereavement, despite the fact that these behaviours differed significantly from those in a non-bereaved group. Furthermore, research suggests that paid carers lack confidence in the value of supporting bereaved individuals with IDs generally (McHale *et al*, 2009). It is argued then that alternative perspectives to support for bereaved people with PIMDs are welcome.

A need for alternative perspectives

Apart from the obvious implications that a cognitive view has for bereavement support, there are a number of additional issues that point to the need for engagement with alternative perspectives. First, and contrary to the suggestion of Meeusen-van de Kerkhof *et*

al (2006), a number of case studies illustrate that people with PIMDs do in fact show a *range* of grief responses, including ‘mournful crying’ (Oswin, 1985; Oswin, 1989; Phillip *et al*, 2005; Sinason, 1992; Tuffrey-Wijne, 2014; Young *et al*, 2014; Young & Garrard, 2016). While the expressions of grief bear similarities across the ID spectrum, and indeed to those without an ID (Dodd & Guerin, 2009), it is expected that there *are* fundamental differences in understanding for people with a severe degree of cognitive impairment. However, the cognitive framework does not, at least explicitly, account for these reactions. Second, the limits of a cognitivist approach, have been argued in light of the wider socio-contextual factors that mediate experiences of loss in people with PIMDs (Young, 2016). For example, not being told about the death and lack of acknowledgement that the loss is significant to the person may act as barriers to grieving. These important aspects are not attended to within the cognitive framework. Accordingly, it is suggested that such a perspective may lead to further neglect of this group and serves to distance us more from considering the impact of these experiences. It is for these reasons that engagement with family and paid carer perspectives are necessary: to consider their views in conceptualising bereavement and support for people with PIMDs.

Motivations and aims of the research

Combined with a lack of empirical research and clear theoretical direction, one further motivation led the present authors to consider how bereavement is conceptualised in this context. In the context of a charitable organisation providing a service for family carers, both parents and professionals frequently request advice on how to support their bereaved relative or client. It is noted that no specialised counselling or approaches are available to engage the person in ways that support them with grieving. In the spirit of the organisation, it is important to represent both family and paid carer perspectives as key sources of meaning

in the intricate network of support, particularly given the increased level of care involved for people with complex healthcare needs.

The current study provided carers with an opportunity to share their perspectives in order to elucidate how they make sense of bereavement in this group. One previous study adopted a similar aim and methodology, and included a range of IDs (Handley & Hutchison, 2013). Whilst their study aimed to explore decisions around support in light of perspectives on bereavement, the current study aimed to draw upon how carers recount past bereavements, their responses to grief reactions and decisions around support, as a means of addressing the research question: how do carers conceptualise bereavement in people with PIMDs? Carers' *experiences* will also be important here; the ways in which they describe these aspects will partially reveal how they make sense of the person's experience, with a degree of interpretation on the part of the researcher.

Method

Design

Since the current study sought to examine how carers make sense of bereavement, a phenomenological approach was appropriate. Given that the study was conducted by researchers within a support organisation, it was important that the approach to analysis left room for this expertise and their interpretation. Therefore, data were subjected to Interpretive Phenomenological Analysis (IPA). The design of the interview schedule consisted of eleven questions (Table 1), engaging with two important areas: a) how carers described the experience of bereavement (including the person's understanding and overt grief reactions) and b) how the person was supported and responded to. Essentially, the opening question was to facilitate this recounting, which then led to opportunities for the participant to explore these with prompts from subsequent questions (Smith *et al*, 2013).

[Insert Table 1 here]

Participants

Purposive sampling was employed; those carers receiving family support from the organisation were best situated for the purpose of this study. All families involved with the organisation care for someone with PIMDs, as defined in Nakken & Vlaskamp (2002): limited communicative abilities, and additional significant physical and/or sensory impairments. Initial assessments by the Family Support Service identified these multiple conditions. Participants were from across Scotland (see Table 2 for demographics). Family carers were mothers caring for a son or daughter with PIMDs who experienced the death of a close relative. Years caring ranged from seventeen to forty-seven years. Paid carers, all females, worked in a day-centre or in a residential setting where a number of people with PIMDs, known to the organisation, were cared for. In this context, there was a number of service user deaths and paid carers responded to the interview by drawing on a number of relevant cases.

The first author (the interviewer) and third author are researchers with experience of working with families on issues surrounding bereavement and loss. The third author was familiar with many of the participants, while the first author met them through the research project. The second author had over 40 years of experience in disability research, and supported many families, including those involved in the study, for over 20 years. The multi-levels of familiarity and expertise rendered the research team suited to engaging with data analysis.

[Insert Table 2 here]

Procedure

Carers were invited to take part in the study by letter, detailing their right to withdraw at any time and that data would be anonymised. Written consent was obtained. One-to-one interviews were conducted and recorded by the first author at a place most convenient and

comfortable for the family carer (e.g. the carer's home, a day centre or a quiet public place). Participants were offered the attendance of someone known to them from the Family Support Service, to which two family carers agreed (Ruth and Fiona). It was not possible to conduct one-to-one interviews with paid carers, due to their time constraints. Group interviews were therefore conducted and recorded; one interview with one day-centre, and the second interview with one residential centre, where the corresponding centre managers were present. Although a number of paid carers attended these group interviews, one paid carer tended to speak on behalf of the group, whilst the others intermittently agreed and prompted the 'speaker' with names of individuals. Thus, only one paid carer from each centre was been counted as being interviewed. Interviews ranged from between approximately 30 minutes and 90 minutes, and were transcribed by the first author. A post-interview telephone-call provided an opportunity for reflection and to identify if further support was required.

Analysis

All transcripts were analysed using IPA according to the six-stage strategy outlined by Smith *et al* (2013) (see Table 3). In accordance with Elliot *et al*'s (1999) good practice guidelines for qualitative research, the third author acted as auditor by checking that themes and interpretations were reflective of all transcripts.

[Insert Table 3 here]

Ethics

The ethical implications of the study were carefully considered. Sufficient information was given to participants and appropriate support was offered. This was part of a much wider project to record experiences of carers supporting people with PIMDs to engage in grief work. An independent review was provided by the University Research Ethics Committee, and ethical approval was granted.

Results

Analysis revealed two super-ordinate themes, ‘difficulty articulating the experience of loss’ and ‘making sense of bereavement through familiar patterns’, abstracted from three of sub-ordinate themes (see Table 4). Quotations from the interviews are presented and interpreted below, serving to illustrate and contextualise themes more fully.

[Insert Table 4 here]

Theme 1 – Difficulty articulating the experience of loss

This super-ordinate theme aims to capture how carers struggled to conceptualise the cognitive and emotional aspects of the person’s bereavement experiences, leading to a narrative progression from this complexity to issues of rights and participation.

A different kind of understanding

This sub-ordinate theme illustrates the difficulty in characterising the person’s comprehension of death and loss, which led carers to conceptualise “understanding” as having an emotional dimension. On the surface of the narrative, as it is above, it appears that parents were arguing *for* cognitive capacities by using phrases such as, “he understands perfectly” and “I think he understood”. This is contrasted however with the observation that the ID was adversely affecting the person’s ability to understand:

You couldn’t explain to her - you’re Dad had died. Couldn’t explain to her - you’re Dad’s not going to be coming back. Because I don’t know how much she would have understood...They just sort of think, as we did, that because of the damage to their brain and the lack of knowledge, that the whole thing has gone over their head. [Liz, Parent]

I’m not sure they understand that somebody has died or even if they have the ability to understand that... [Gemma, Paid carer, Day Centre]

As these two quotes illustrate, there is an incongruity within the narratives of the carers around the person’s understanding. This ambiguity is best exemplified here, but points to an interpretation of what is meant by “understanding”:

Yeah, I think in some ways there's such a lack of resources because nobody has really, until maybe recently, thought about that they do have a capacity to feel loss - they have a capacity to understand. [Clare, Parent]

In this case, it seems that emotion bears relevance to the person's comprehension. Further clarification on this emerges when we consider the themes: 'social regulation of emotion' and 'a change to familiar patterns'. It is worth noting in anticipation of these themes that carers were at times describing emotional insight – in the above quote it is the feeling of loss - as a different kind of understanding, but not an understanding of death. Overall, it is clear that carers are viewing the bereavement experience initially through a cognitive lens, even if it is to suggest that capacity is reduced.

Social regulation of emotion

This second sub-ordinate theme relates to a strong consideration of the socio-emotional aspects in the majority of transcripts. In some cases, the person's reactions exceeded the carer's expectations, which had been influenced by a perception of cognitive impairment. However, this resulted in carers not knowing how much the person understood about the loss. The emotional insight of the bereaved person was often referred to as a "sense" or a "picking up on" the feelings of others.

So I think they, even though you couldn't explain to them anything, we felt that they understood the sombreness of sort of the funeral and what was happening...I think that there's no doubt they're aware...See we took two boys to Dillon's funeral and I mean, whereas I say the behaviour of one could have gone either way, I mean he seemed to, he seemed to be totally aware of you know? Of the occasion... [Helen, Paid Carer, Residential Centre]

But she was caught up in all the emotion that we all showed. She withdrew. She sort of cut herself off. [Liz, Parent]

In contrasting the above two quotes, it is clear that the emotional insight of the bereaved person can have different consequences which further evidence to the carer that they experience something of the emotion of others.

In addition to the effects of emotional reactions on the bereaved person, carers highlighted the bi-directionality of this interaction. It was apparent that there was an interweaving of emotions between the person with disabilities and those around them; the person with disabilities observed and experienced the reactions of those around them, whilst they in turn felt and were changed by the responses of the person with disabilities:

No, she helped me tremendously, because...sharing the grief with her and seeing how she coped with it helped me to cope with it too...and everybody that had gone to my brother's funeral had said, "seeing Katie dancing to the music and it was a lovey joyous occasion" ...It made it lovely for them too so she brought something from her understanding to all of us as relatives as well so I think it worked as whole family for us. [Ruth, Parent]

I tell you something – my daughter, in her own way, has touched more lives than probably a lot of people. There's a lot of good things come out of life because of my daughter. [Liz, Parent]

This theme relates intricately with the difficulties in articulating the bereaved person's experience. On the one hand, carers are aware of the bereaved person's issues with processing information, but at the same time they see the powerful interpersonal effects of emotion. Together with the previous sub-ordinate theme, this represents a different kind of understanding for carers: an emotional understanding, which transcends the intellectual impairment and challenges their initial perceptions of how cognitive limitations impact on the experience of bereavement.

A right to participate

While interpreting decisions around support, this sub-ordinate theme reveals that uncertainty around what is understood and felt shifts the focus away from facilitating understanding to an emphasis on the rights of the bereaved person to participate in grieving rituals.

This emphasis is most strongly exemplified where parents expressed concern about protecting the person from loss. In some cases, parents regretted not telling the person about the death, and preventing them from attending grieving rituals in the past. In light of this, parents have adopted the approach of enabling and including people with PIMDs in funerals. This principle of inclusion is particularly noticeable in the following quote:

Tom had never been to a funeral, but I'd made up my mind that any other cremation or funeral, he will go to because I feel that it is only right...Tom was there and it was lovely to see him there and he, I think he actually sort of appreciated the situation he was in because obviously there was a lot of tears...[Gail, Parent]

In analysing the transcripts of the *paid* carers, it is clear that the ethos of inclusion is accentuated by the fact that they have a crucial supportive role to play in the lives of those they care for:

Well it was just our own feeling that we felt we had to, we were there for them as part of our role really to support them...I thought it was quite important and for them to participate and that [Helen, Paid Carer, Residential Centre]

Notice that carer decisions around participation is based on rights rather than any strong reference to understanding or how this participation may impact on the grieving process. It may be argued that difficulty around articulating cognitive aspects of the bereavement experience, as evidenced in the previous sub-ordinate themes, shifts the focus to 'normative' aspects of grieving and ritual and is termed here as participation.

Theme 2 - Making sense of bereavement through familiar patterns

This super-ordinate theme captures the idea that change, in the experience of familiar routine and relational interactions, is a central aspect of considering the bereavement experiences and support needs of people with PIMDs. Carers were found viewing bereavement experiences through the lens of what they believed to be already familiar to the person. This appreciation appeared to provide some guidance around appropriate support, especially given the lack of external support and resources. Two sub-ordinate themes emerged here, ‘a change to familiar patterns’ and ‘support shaped by familiarity’.

A change to familiar patterns

By recounting the changes consequent to loss, this sub-ordinate theme captures carers making sense of bereavement through familiar patterns, and was defined in terms of how these were disrupted or no longer part of the person’s life:

I just know that she knew her dad was there and then her dad wasn’t. [Liz, Parent]

Well, I think from experience, I think you’ve to, you have to put yourself in their position to try and imagine yourself in their position and if you had something taken away from you or someone you cared for disappeared from your life suddenly and no one told you where they’d gone, how would you respond, how would you feel? I think you’ve got, well I would imagine that just trying to stand in that persons shoes for a while and see, just put your mindset into that, how would you feel for yourself and you had limited understanding but you knew that familiar sound or that smell or that taste or something and it was never there again, how would you feel? [Gail, Parent]

The described immediacy of these changes convey how carers imagine the experience of loss for the bereaved person: as a stark contrast between then and now. Elements of a cognitive conceptualisation are tentative, but present here. In elaborating on this conceptualisation however, carers again reflect the emotional aspects. There was a strong view that the bereaved person was especially sensitive to the emotional changes of others:

I think her feelings were more to do with us, her immediate family being distressed.

[Ruth, Parent]

I noticed he had a period, probably while the emotion was around the family, around the immediate time he was quite quiet, I noticed that. [Clare, Parent]

This last quote is specifically telling about how this parent makes sense of her daughter's experience. She attributes her daughter's emotion to the grief reactions of others, more so than to the other consequent changes. This further highlights the strong emphasis that is placed on emotional insight.

Overall, the power of these illustrations are found in their ability to bring us closer to the experience for people with PIMDs, which is not supported by a full understanding of death but is painfully felt by the changes surrounding them. Here, the cognitive and emotional themes re-emerge as enmeshed.

Support shaped by familiarity

Just as changes in familiar patterns serve as a principle aspect of how carers make sense of bereavement, this sub-ordinate theme demonstrates that familiar concepts and experiences shape decisions around support.

Despite the pervasive uncertainty around bereavement support, carers had a real sense that familiar patterns were a significant aspect of this care, which took the form of using already established concepts in faith and religion:

If you try to not give an explanation she becomes distressed so she needs to have some form of explanation, be it in a very simple form or like a story about heaven and waving to the sky. That might seem silly to others but she can take that on board and that's how we've dealt with it...So Irene goes to church with me so she would understand that concept... [Ruth, Parent]

We did try to explain to him in our way about that she'd gone. We did try to explain about his Nan loss, about her dying in the sense that she had gone to live with Jesus. She wasn't here anymore, had gone to live with Jesus, because Leon had always been involved with the church. [Clare, Parent]

The familiar concepts here relate to aspects of how the family has made sense of death previously, with the purpose of overcoming the presenting cognitive limitations as a way of regulating emotion.

In one case, there was a strong awareness of how previous losses, as familiar experiences, helped to develop some concepts around death, facilitating more recent understandings. Carers were using past experiences of significant pets as part of this process. The familiarity of these experiences mean that the person could connect with a concept that is difficult to form abstractly:

We explained to Matt that his Dad had died just like Tigger his cat [Fiona, Parent]

The following quote demonstrates the significance of this for Gail, which can be traced back to the person's early years. Thus, familiar patterns suggest a preparation for future bereavement; and clearly points to some cognitive conceptualisations:

You can prepare them for that and I suppose you could actually prepare a young person and talk about death when they're younger - you know bring in. Everyone's got pets and...because when our boys were small, if any of their - you know the rabbit died, the budgies died. In fact, Tom had two budgies...and he died and we showed him where we buried the bird and he kept going out, digging it up and bringing it back in because he was so distressed...and then Bluey when the blue bird died he understood then that the blue one had gone to be with the budgie bird. [Gail, Parent]

In summary, this sub-ordinate theme captures cognitive conceptualisations of bereavement experiences as carers attempt to support development of understanding and

overcoming of cognitive impairment. Interestingly, the emotional insights resurfaced here as carer's appreciate the function of cognitive understanding in regulating emotions as part of support.

Discussion

Although there have been limited but significant theoretical contributions to the conceptualisation of bereavement in people with PIMDs, no previous research has sought to explore what perspective carers might lend to this discourse. The present study provided family and paid carers with this opportunity and found that they mainly made sense of bereavement through the inextricable links between cognition and emotion. Decisions around support sought to overcome the challenge of uncertainty by focussing on participation and fixed patterns familiar to the bereaved person. The current reflections encourage a more holistic view of bereavement in this group, in the face of the current cognitivist approach to this area.

Current findings in view of theoretical contributions

In revisiting the work of Meeusen-van de Kerkhof et al (2006), we can find parallels between their work and the findings of the present study. The authors describe the experience of bereavement for people with PIMDs as predominantly a “breach of fixed patterns”, against a lack of realisation about death. This can partly be reflected by the carers in the current study as they highlight the importance of familiarity in conceptualising loss and support. It is further suggested by these carers, however, that people with PIMDs have a level of emotional insight that has implications for how we make sense of what they understand about loss and how facilitating an understanding can serve a regulatory function. In contrast, the importance of this emotional insight is not discussed in the cognitive framework, which is therefore limited as it fails to integrate this important aspect.

It is also important to consider what bereavement support is suggested by Meeusen-van de Kerkhof *et al* (2006). ‘Counselling’ for bereaved people with PIMDs is mainly characterised by making the person experience change acutely. Certainly, in the current study, carers used a variety of ways to support the bereaved person, including the use of items that were related to the deceased. More significantly though, support took the form of enabling the person to participate in grieving rituals. Although perhaps not deliberately, this form of support appears to be reserved for more able individuals in the cognitive conceptualisation, but which seems to be an important part of providing bereavement support.

Current findings in view of previous qualitative work

The current study adopted a similar methodology to the one outlined by Handley & Hutchison (2013), and serves as a useful backdrop against which we can make sense of the current findings. A number of similar themes emerged in both studies; first, the sense of uncertainty around bereavement support, particularly around not knowing what the person understands about the loss. Second, this had clear implications for how carers made sense of grief reactions and what this might tell them about the experience of loss. The result in both studies is that carers sought to conceptualise loss in comparison to ‘normative grieving’. This is related to the third point; carers in both studies had seen attendance at funerals as being a *right* of the person and that support *should* enable inclusion in grieving rituals. Fourth, both papers highlight the importance of interactions between the person with IDs and others in mediating grief responses.

Although there are similarities between the current study and that of Handley & Hutchison (2013), the present findings focus specifically on a group of people who are often marginalised even within the disability field. How carers conceptualise bereavement in people with PIMDs was central to this study and contributes to a wider discourse about how

we define PIMD. This group may often be perceived as in need of support and not in terms of how they can impact and shape the lives of others (Porter *et al*, 2001; Simmons & Watson, 2014). When one considers them as relational and emotional, rather than in terms of their cognitive impairments, one begins to feel challenged in our perceptions of what they are capable of understanding. The current study illustrates this narrative process from a carer's perspective, that may otherwise be missed. Furthermore, it directly relates these findings to recent considerations of how bereavement is conceptualised in this group.

Implications for practice and training

Dogmatic assertions around bereavement support for people with IDs has been questioned (Clegg & Lansdall-Welfare, 2003). The resulting orthodoxy that, for example, people with IDs should attend the funerals (Oswin, 1991) may be influenced concomitantly by beliefs around universal responses to grieving and normalisation. However, in responding to this, the importance of participation as a principle cannot be sufficiently understood without an appreciation for the broader themes of uncertainty running throughout the carer narratives in this study. This is rarely given consideration: carer's conceptualisations may be more accurately described as an ongoing conflict between cognitive and emotional aspects and how they reconcile these when making decisions about support. In recognising this difficult discourse, there is a clear need for training to take account of these theoretical discussions and their impact on practice.

A considerable number of works in the field have, as their foundation, a variety of approaches to grief: cognitive approaches, attachment-based perspectives and theories of grief (Young, in press). This dialogue can be used to deliver the basis for training on bereavement issues in IDs. For instance, the narratives offered by carers in this study, can offer a rich perspective on real issues that many other carers may be struggling with. The crucial point: theoretical contributions should not preclude certain types of bereavement

support, but instead encourage discussion around them. Carers in this study, for example, have been able to testify to the importance of support that may not be explicitly considered within particular frameworks (e.g. engagement with rituals) for people with PIMDs.

Limitations

The current study is limited to a relatively small number of mothers and female paid carers selected by purposive sampling. This group is therefore not a representative or homogenous sample caring for people with PIMDs. The current study does not fully consider the differences existing between family and paid carers. A crucial difference, given that there may be some disagreement between them, which have implications for practice. In addition, the present study focused on participants who were Caucasian Scots. It would be interesting to engage with other cultural perspectives. Furthermore, similar studies have noted the extent to which design and approach could influence results (Handley & Hutchison, 2013). These limitations may include the retrospective design of the study, biased recruitment and the influence of the researchers' interpretation of the data. Particular to this study, family carers and paid carers were interviewed in different contexts. Family carers were interviewed one-to-one, whilst paid carers met in a group context with their manager present. The silence of many of the paid carers during these interviews might suggest that the setting was uncomfortable for them. Therefore, the wider voices of the paid carers have not been fully heard. Nonetheless, these cautions should not overshadow the individual carer perspectives, which authorise a rich variety of ways to consider the experiences of bereavement for people with PIMDs.

Routes for Further Research

It may be of interest to family support services for research to explore the ways in which the themes emerging from this study can facilitate discussion and support for carers. It could enquire as to what emerges from these discussions, within support and also within

training for paid carers and professionals. Of particular concern may be the neglect of other issues influencing the experience of loss in people with PIMDs, and those supporting them; for example, how parents and carers conceptualise attachment in this group, and how this bears relevance to bereavement and loss. A full consideration of the factors impacting on attachment relationships would be beneficial to many areas of trauma and loss in people with PIMDs.

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Tables

Table 1. Semi-structured interview questions

Question
<ol style="list-style-type: none"> 1. What is the experience of bereavement for people with PIMDs? 2. Was the person told about the death or loss? 3. How do you think the person understood the loss? 4. Did the person express any reactions to the loss? <ol style="list-style-type: none"> a. Were there any emotional changes in the person? b. Were there any behavioural changes in the person? c. Were there any physical changes in the person? d. Did the loss affect the person's relationships with others? 5. Are people with PIMDs being supported when they go through a period of bereavement and loss? <ol style="list-style-type: none"> a. Why do you think that? b. How do you think individuals with PIMDs can be better supported?

Table 2. Demographics of participants

Pseudonym	Relationship to person caring for	Years caring	Bereavement
Gail	Parent	47 years for son (Tom)	Grandfather died
Ruth	Parent	17 years for daughter (Katie)	Grandmother died
Clare	Parent	21 years for son (Leon)	Grandmother died
Fiona	Parent	41 years for son (Matt)	Father died
Liz	Parent	44 years for daughter	Father died
Gemma (Day centre) (10 paid carers present)	Paid carer	Unknown	Family bereavement
Helen (Residential centre) (4 paid carers present)	Paid carer	Unknown	Service users died

Table 3. Summary of analysis

Strategies as described by Smith et al (2009)	Description of work involved
1. Reading and re-reading	Listening to the recorded interviews, whilst reading the transcripts, reminding the interviewer of the tone of the respondent. Further readings of the transcripts allowed a deeper engagement with the narrative.
2. Initial noting	Initial noting about language use on a sentence by sentence basis. Conceptual notes were also taken when considering the context of the experience being shared. Text which seemed to hold importance was underlined.
3. Developing emergent themes	Themes were identified from the relationships between notes and were articulated in language that balanced the data and conceptual levels of analysis (e.g. ‘socially regulated emotion’ emerged from the impact of others’ grief on the person with PIMDs).
4. Searching for connections across emergent themes	Some themes were discarded on the basis of the research question (e.g. difficulty balancing physical support and emotional support for the person with PIMDs). Themes were clustered if they were related (e.g. ‘lack of understanding’ was related to other cognitive-related themes such as ‘the importance of familiar patterns’). NVivo (version 10) was used at this stage to compile and manage extracts that were relevant to the emergent themes
5. Moving to the next case	Each of the first four steps were conducted for each transcript, allowing for new themes to emerge.
6. Looking for patterns across cases	Identification of themes occurring across cases and were closely related. This involved bringing themes together theoretically (e.g. ‘a change to familiar patterns’ and ‘support shaped by familiarity’ were brought

together under the superordinate theme ‘making sense of bereavement through familiar patterns’).

Table 4. Structure of themes emerging from analysis

Superordinate and subordinate themes

1. Difficulty articulating the bereaved person's experience
 - a. A different kind of understanding*
 - b. Social regulation of emotion*
 - c. A right to participate*
2. Making sense of bereavement through familiar patterns
 - a. A change to familiar patterns*
 - b. Support shaped by familiarity*